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Donna Lavin

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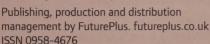
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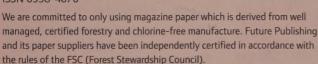
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## editorial

## Working towards wrong conclusions

The pilot programme to move people off Incapacity Benefit (IB) and on to Employment Support Allowance (ESA) has now, in the jargon of such ventures, been "Rolled out". The aim of this programme, as stated by Employment Minister Chris Grayling in the last issue of this magazine is to get more disabled people back into work and, off the welfare state.

The transfers will be effected by means of an assessment which has been roundly and repeatedly condemned in several quarters as not fit for the job – an irony which is doubtless not lost on some of those being subjected to it.

But the fact is that it's not merely the assessment that's flawed. It's the very premise and approach to the process which is wrongly focussed.

In the first place, the assessment is designed to establish the ability and capability of the assessee to undertake work. This means several problems raise themselves from the outset.

First, the term "Work" appears to be generic with a probable focus on the physical. Self evidently, someone's ability or lack of

it to scratch their own head or pick up a pencil would have little relevance if, for instance, they wanted to work as a psychotherapist.

Next, the entire assessment dwells on the problems (or lack of them) which the individual presents in respect of ability to work. Whereas in reality, and as those disabled people who've gone through the process of trying to get a job well know,

ability or lack of it to scratch their own head or pick up a pencil would have little relevance if, for instance, they wanted to work as a psychotherapist \$99

the majority of factors which prevent us from doing so are outside us and outside our control. They're much more likely to be to do with the prejudicial attitudes or discriminatory assumptions which prospective employers make, often at the point that they're deciding that we're not even worth an interview.

It's these which are the barriers to work which should be demolished.

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#### your rights, your voice, your life





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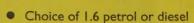
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### newsview

Sayce review accentuates the positive

Radar chief executive Liz Sayce is completing a review of employment services offered to disabled people. She's determined, she tells Sunil Peck, that it looks forward to opportunities

Liz Sayce sees her independent review as the opportunity to put the aspirations and wishes of disabled people keen to work at the heart of specialist support.

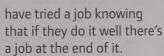
The review of the services delivered via Work Choice, the Work Programme and Access to Work draws on existing research. But she's been talking to disabled people's organisations, charities, unions and employers since January.

She says that a number of issues have arisen around Access to Work, including raising awareness of the scheme beyond larger companies and the public sector.

"A lot of other people have never heard of it, particularly small businesses. So we're looking at ways in which that support can be better known."

She's also identified a need to raise awareness of Access to Work among health professionals. She cites the case of someone on a spinal injury unit where occupational therapists talked to him about opportunities to sky-dive and walk to the North Pole but who said nothing about support to work.

"The other big theme is that there's evidence from the learning disability and mental health fields that seems to show that for an increasing number of people, the best chance of employment is if you're supported to start thinking about getting a job in the beginning rather than going through a lengthy series of stepping stones like training programmes, college courses or sheltered experiences. We've come across interesting examples where people have been able to do work placements where, rather than going through a standard interview process, people



"Some major employers have offered the experience of practising interviews and CV skills in the workplace rather than it being done in a college or disability organisation."

But with unemployment rising, is it realistic to expect that disabled people are in a good position to gain and retain work - even if they do have better support?

"The mistake that was made during previous recessions was that nobody did anything in preparation for the upturn in terms of disability so disabled people lost their jobs and didn't get them back. So it's worth trying to improve the system so that as jobs become available, disabled people have got a really good chance of getting them. That's one of the reasons I've been looking at apprenticeships and the business sector which are areas that are potentially growing.

"Investment is difficult at a time like this but I think that some of the ideas we're looking at are costeffective. For example, there's research that shows that for every pound spent on Access to Work, the Exchequer recoups around £1.44. It's about using money well to enable disabled people to participate fully."



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## newsupdate

#### **Confusion after mixed messages on res care DLA**

**Sunil Peck** 

People living in residential care continue to worry about being able to afford the cost of transport after 2013 as the coalition Government sends out mixed messages about the future of the mobility component of Disability Living Allowance (DLA).

The coalition Government has been facing accusations of callousness since it announced plans to cut the mobility component of DLA for people in residential care last October. But following a vociferous campaign from disabled people and allies, an exchange between David Cameron and Labour leader Ed Miliband during Prime Minister's Questions on 23 March appeared to indicate a government u-turn.

Asked to explain why he proposed to remove the funding which 80,000 people rely on to cover travel costs, David Cameron said: "The short answer is that we are not".

His response was at odds with proposals set out in the Welfare Reform Bill.

On hearing David Cameron's answer to Ed Miliband, Anthony Rew (pictured), who lives in



Woodford Court care home, reacted by saying: "That's brilliant because if they take away the money people like me will not have any money to go out or do anything."

But when pressed by Ed Miliband to scrap the proposals in the Welfare Reform Bill, Cameron said that the future of the mobility component was subject to a review.

Later that day in the budget, Chancellor George Osborne repeated plans to remove the mobility

component. But the date was put back to 2013, a year later than the date announced in the 2010 spending review.

Commenting on the continuing uncertainty, Anthony Rew said: "What I can't understand is that David Cameron did have a disabled son. He must know what disabled people go through. Surely to god he should understand why this is so important."

The Shadow Work and Pensions Secretary Liam Byrne urged David Cameron to "get a grip of his welfare reform proposals".

He said: "David Cameron said he was going to save mobility payments for people living in residential care. Now we learn from George Osborne's budget the Treasury is cutting nearly 50 per cent more than originally planned."

Neil Coyle, Director of Policy at Disability Alliance, added: "It would be very welcome to have it confirmed that Welfare Reform Bill plans are being withdrawn which would cut help in care homes for 80,000 disabled people and take over two billion pounds from DLA".

A Department for Work and Pensions spokeswoman said: "The Government has listened to charities and other stakeholders and will no longer remove this payment from October 2012. Instead, we are reviewing the mobility component as part of our wider reforms of DLA."

But she was unable to say when the review will be complete, how mobility payments will be calculated from 2013 when DLA is replaced by the Personal Independence Payment, or if people in residential care were likely to receive less money.

## newsupdate

## Miller reform plans get predictable cold shoulder



Ian Macrae

The Government has published its response to the consultation on reforming Disability Living Allowance (DLA).

According to Maria Miller, Minister for Disabled People (pictured) almost 5,000 individuals and more than 500 disability organisations responded to the consultation.

But some disabled people believe that the Government has been highly selective in finding support for the approach to reform which had been

outlined prior to the start of the consultation process.

Kaliya Franklin of the online campaigning group The Broken of Britain told Disability Now: "We are very concerned that the Government seems to have cherry-picked the responses they like and ignored the rest, resulting in a consultation response that fails to recognise the issues raised by disabled people."

Giving more details of the response, Maria Miller said: "During the consultation period we received many letters and emails from individuals and disability

organisations who said that the benefit needs to be updated and made easier to understand."

She confirmed that DLA would be replaced by the Personal Independence Payment (PIP) and confirmed that this new benefit would be subject to "more transparent assessment" which even existing DLA recipients would have to undergo.

This will do nothing to allay the concerns of those who feel that this approach represents a medicalisation of entitlement to extra payment which activists and allies view as a recognition of the additional social costs of disability.

Richard Hawkes, Chief Executive of Scope (The charity which publishes Disability Now) said: "Daily life costs more if you are a disabled person, and for many Disability Living Allowance is a real lifeline. We recognise that it needs modernising, but we are concerned that reform is motivated by a desire to cut costs rather than improve the system. The Government's response to its consultation doesn't

allay those fears".

Further affirmation of the Government's intent to focus PIP more tightly on medical evidence and personal impairment emerged in other comments made by the Minister. She said: "There will be no automatic entitlements where people with certain health conditions or impairments automatically receive specific rates of benefit, as we don't want to define people by their disability. Instead we will look at each individual case and the impact of a person's impairment on their ability to live independently."

But commenting on the Government's response, Neil Coyle of the Disability Alliance told us: "The Government has failed to respond to questions focussing on the potential knock-on costs to other public services of cutting direct help for disabled people. DWP also remains reluctant to publicly estimate how many disabled people might lose help as a result of the cuts, which include abolishing low rate care payments. Our analysis shows that removing all support from the 643,000 people receiving low rate care payments (including associated mobility awards) would cut £1.4 billion - only two thirds of the Government target."

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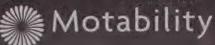


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## ruthpatrick

### **Action and academe united for change**



Looking forward, Ruth Patrick trails a day of action against cuts and welfare reform coming soon to the streets of London

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particularly hectic week recently saw me, first in speaking on disability issues at an academic conference, and then in marching with hundreds of thousands of others on the TUC "March for the Alternative". At both, thoughts of disabled people's struggle for full equality and human rights were at the forefront of my mind.

Out marching, one feels solidarity with the fellow protestors - part of a common cause loudly challenging the current Government's welfare cuts and benefit reforms which so unjustly target and penalise disabled people. Never did the Government's refrain

"we're all in it together" ring so true, except we're in it together against the Government not with them. On the other hand, the academic conference was a rather lonely affair - an opportunity to present my latest research and to try and give more voice to disabled people's own perspectives on the **Employment and Support** Allowances reforms. These two occasions got me thinking on how best to campaign for real and meaningful change that furthers the cause of disabled people and contributes towards the broader goal of equal life chances for all.

This question is particularly pertinent in the current climate, where the need to campaign on and oppose much of government policy has never been more urgent. But, where should we place our undoubtedly limited energies and resources, so that they have the most resonance and effect?

The UK Disabled People's Council (UKDPC) and various disability charities are planning a mass day of action in May where they hope to bring thousands of people together for a march, lobby and rally in protest at the Government's reforms

Commenting on his aspirations for the day, Jaspal Dhani of UKDPC said: "The day of action is an invaluable opportunity for all those with a concern for disability issues to come together and express their dissatisfaction with the pace and direction of the Government's reform agenda. We also need to show the very real damage that these reforms could do to disabled people's quality of life, fundamental human rights and scope for independent living. Getting

One feels solidarity with the fellow protestors part of a common cause loudly challenging the current **Government's** welfare cuts and benefit reforms which so unjustly target and penalise disabled people 🥮

this message out there – to media and the Government is the central goal of our day of action!"

An ambitious goal, undoubtedly, but one that will hopefully be realised at least in part by the actions of those taking part in the day. What I am clear on, however, is the importance of getting out there and responding to the Government's reforms, making a case for an alternative, more just way forward.

• For more information on the 11th May day of action see: www.ukdpc.net

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## disabilityrights

### Personalisation: no silver bullet

ike a lot of people I have long been worried about a policy that's meant to transform support for older and disabled people, but which is framed in terms of jargon like "personalisation".

Yet this policy is still being hyped by government, although now after three years and £1 billion for "transformation", with the process not half achieved, government has offloaded responsibility and allowed just £1.2 million to complete the job. What does this bode for disabled people and other service users after all the claims made for personalisation and personal budgets, as eligibility criteria tighten and personal budget ceilings come down?

We can get some idea from the findings of a survey of personal budget practitioners recently launched by the London Self-Directed Support Forum, which provides findings from front line workers. It draws on the experience of 40 workers from 19 different London authorities. While it is a small study, the independence and complexity of its findings



It's been touted as the holy grail for giving full choice and control. But, says Professor Peter Beresford, beware of buzz words like "personalisation"



paint a valuable if worrying picture.

Most practitioners report that they and service users don't understand self-directed support. Most workers

don't think new systems of assessment ensure more choice and control and that people aren't offered independent support to complete self assessment forms. Most

don't understand the "resource allocation system" - the RAS, which was meant to be personal budget's unique selling point. In a majority of cases the RAS neither seems

to be matching need or come closer to ensuring adequate financial resources. It has mostly tended to reduce people's budgets.

In most settings, there are still restrictions on what people can purchase with their personal budget - which flies in the face of the essential point of moving to personal budgets. For a sizeable minority of people there still aren't annual reviews and as for the Government's demand that the system should be outcome based.

Most workers don't think new systems of assessment ensure more choice and control and that people aren't offered independent support to complete self assessment forms •

an outcome based review process is still not in place for around half of cases.

Not all is doom and gloom however. In a

number of cases we are seeing more creative support plans, a clear definition of a service brokerage scheme and support plans getting the go ahead. In about half of cases the brokerage service is rightly separate from support planning. In most cases there is ongoing support. But this is hardly the kind of transformation we were promised and it is clear that we are still far from the "transparent" and "debureaucratised" system of customized support that

disabled people and other social care service users were promised. Perhaps most worrying, at least half the participants in this survey think that personalisation is a tick box exercise - which does not make for meaningful improvement. This survey clearly needs to be extended. But it offers government an early warning that it is probably going to have to go back to the drawing board if it is serious about "personalisation" and "self-directed support" for all.



## mediawatch

## Henry defiant on stammering spoof

Comic Relief has been criticised for scoring something of an own goal in this year's fund-raising TV comedy fest. **Paul Carter** reports

would have become a

thing of the past,

particularly from

broadcaster, and

especially from

Comic Relief."

the national

he founder of Comic Relief, Richard Curtis has been forced to apologise after a sketch parodying *The King's Speech* starring Lenny Henry was slammed by stammering campaigners for being offensive and disablist.

In a formal complaint to the BBC over the sketch, seen by *Disability Now*, the British Stammering Association (BSA) expressed "utter dismay" and called for a public apology for the "serious and widespread offence to people who stammer and those who support them."

It says: "It may not have occurred to you, but stammering, like other disabilities, is covered by the Equalities Act and people who stammer have the right to protection under the Act, just as, for example, people with cerebral palsy. What might we look forward to next time — Lenny Henry mimicking someone with cerebral palsy?"

"Somehow it seems, that stammering and children who stammer, are still fair game for public

ridicule. This is particularly Norbert Lieckfeldt, Chief depressing after the Executive of the BSA, says excellent awareness raising the complaint is not about campaign we mounted in his organisation being "pothe wake of the release of faced" or lacking in sense of The King's Speech – we humour, but is more about had hoped that such crass the association with Comic and insensitive behaviour Relief, and the

subsequent hurt it caused to many people involved in raising funds for the charity.

"A show that is designed to raise

the place to mock people with disabilities," he says. "Comic Relief might say it was meant to spoof the film

money for disability is not

"Comic Relief might say it was meant to spoof the film but no-one who does not themselves stammer can tell us how to feel. If that kind of sketch had been shown on the Frankie Boyle show, I doubt we would have complained as bad taste is what one would expect when switching on the telly to watch that.

"BSA have had many responses from parents of stammering children who have raised money for Comic Relief. And so they sat down, as a family, to celebrate their child raising £37.50 for Comic Relief and the first thing they hear is his stammer being mocked and, as one mum said to us, in exactly the same language the bullies in his school use every day.

"Following this, we have had stories about youngsters on the Monday morning following the show, cancelling their participation in the school play because they don't want to get laughed at; of a speech therapist telling us of a

teenager who is desperate to hide his stammer and who, after lengthy therapy, had finally agreed to let the therapist talk to his teacher only to pull out on Monday morning; of a speech therapist telling us of months of therapy required to coax a person who stammers out of mutism because he stopped speaking when his line manager tapped his watch whenever he talked and there are many more stories where these ones come from."

Richard Curtis, one of the

#### What might we look forward to next time - Lenny **Henry mimicking** someone with cerebral palsy?

founders and organisers of Comic Relief said in an interview he was "very sorry" for any offence that the sketch may have caused.

Speaking to Nicky Campbell on BBC Radio 5 Live, Curtis said: "Comic Relief does spend money on bullying, that's one of the things we do deal with here

and stylish bathroom.

in the UK, and I'm sure we were just thinking about the huge fame of that film at that time and the immediacy of it.

"Certainly I'd never want to give that impression [of bullying] and if we did I am sorry about that. It was meant to be a big joke about a very famous film rather than anything to do with the stammering or to cause offence and I would

apologise for that."

However, Lenny Henry, who appeared in the Comic Relief sketch, was less receptive to suggestions of disablism.

"I thought the King's Speech sketch was funny. Very funny," he says.

"I make no apologies for it. The fact we almost raised £100million and people want to talk about that is a bit strange."

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## politics

#### Building the politics of the future

As Disability LIB's funding from the Big Lottery ends, Sunil Peck looks at the impact of the organisation that aimed to give disabled people a louder voice

n 2008, seven groups came together to form Disability LIB (Listen Include Build) for a three-year project to help disabled people's organisations (DPOs) to look beyond the struggle for survival.

The organisations that Disability LIB has been concerned with supporting are those that campaign for disability rights and have a membership and managing board with a majority of disabled people.

With funding worth more than £4 million from the Big Lottery, one key aim in the strategy, according to its director Stephen Lee Hodgkins (pictured, right), has been to facilitate better peer support between DPOs.

As well as publishing toolkits and training materials as part of its strategy, Hodgkins says that Disability LIB has been successful in getting new DPOs off the ground.

"As an example, disabled people in Dudley in the West Midlands came to us and said they'd like to create a DPO there. We helped them facilitate a consultation day and brought in some training

In some conversations with chief executives in the voluntary sector, it's been apparent that they don't see the distinction between disability charities for and **DPOs** of

from an established DPO nearby that worked with them to develop a plan. The Dudley centre has just secured lottery funding of its own."

Tracy McClymont, secretary of the Dudley Centre for Inclusive Living, says that Disability LIB has been a good source of support.

"We've just received a lottery grant and we're about to do some research into advocacy with local disabled people and increase our membership. We're still sorting ourselves out but we want to pass on what we've learned about human rights, social care, education and employment to help other DPOs to succeed."

Although Disability LIB has apparently made great strides towards empowering DPOs in terms of policy and commissioning frameworks, Hodgkins says that there is still some way to go before it is recognised as the authentic voice of out and proud disabled people in the third sector along social model lines.

"DPOs are well established as a social movement but are struggling to define themselves as a sector. In some conversations with chief executives in the voluntary sector, it's been apparent that they don't see the distinction between disability charities for and DPOs of."

As an alliance committed to inclusion, it is perhaps surprising that Disability LIB has been silent on issues such as the future of the social care system and Disability Living Allowance.

"United Kingdom's Disabled People's Council (UKDPC), which is one of

our partners, responded to those consultations. Our focus has been on organisations themselves and we responded to consultations to do with issues like commissioning."

Is Hodgkins aware of any disquiet in the community about how Disability LIB has spent its money?

"There has been some criticism about the regional split, although we do have partners and a presence outside London. We are aware that we haven't had much interaction in the North East."

Hodgkins estimates that there are about a thousand DPOs. But he says that the DPO sector is not too disparate to champion disability rights loudly.

"The more groups the better. It's about sharing resources and working more effectively together, so you could have larger DPOs selling support functions, like marketing and human resources, to smaller DPOs."

It is too soon to say what Disability LIB's legacy will be. With the financial crisis facing DPOs and many wondering where the next

generation of disabled leaders will come from, the future for DPOs looks tough.

Hodgkins says that it is hard to say how much better equipped or stronger DPOs are now to cope with those challenges.

"Some DPOs are stronger. but we haven't been able to reach all of them. We've done some analysis of a hundred DPOs where we compared their income in

2005 and 2009 [and we found that I it increased from £26 million to £40 million.

"The organisations with the most income are centres for independent living and organisations operating on a regional scale. The ones with the least are black and ethnic minority groups and LGBT groups that work on multiple discrimination and equality issues."

#### → Have your say

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## worldview



## Korea's invisible people

Disabled student **Hyeon-bok** reflects on his own life as a disabled person in South Korea and on the low visibility of disabled people in the wider community

have cerebral palsy. So I have some difficulty walking, but I don't let that handicap me when I am with my friends. But many people think I'm very lucky. Maybe they think I'm superman sometimes. They overemphasise my success, the fact that I have a job the same as they do. They think I work harder than people with no disability.

This may be because disabled people aren't that visible in Korea. We're regarded as pitiful and weak. So, they say "can I help you?" When I was younger I got irritable when I heard that. But now I'm more accepting of their help; lifting a bag, giving a seat, etc.

But I like my independent life and I think I can do pretty much anything.

In Korea I've stood out because, for example, I've been the only visible disabled person since I was an elementary school student. I didn't see a single other disabled boy or girl in schooldays. But these days there are some disabled people attending university. And they've formed a group and have a meeting once a month.

In fact, I've found many advantages because I'm disabled. When I wanted to enter my university, I chose an affirmative action initiative for disabled



students. It's been running since 2002, and was designed to give disabled students a high-class education. Now, about 2,000 students enter university each year, and those people are more likely now to find work.

Other disabled Koreans aren't so lucky. When I was reporter on my university's newspaper, I saw people living in segregated accommodation. But they wanted to live independently with their own house, their job, their own leisure time. They said to me, "I save my salary, to buy my house." But now many disabled people find getting their independent life difficult. I think their families are concerned that independent living would be very hard for them. But they still want it.

My friend who has learning difficulties said to me: "In separate accommo-

#### **Market** The right to an independent life is a hot issue in Korea

dation, I often feel tamed because it isn't exciting. I know I may feel uncomfortable when I live alone or with friends. But it will be good experience for me." Some disabled people demonstrate against having to live in this segregated way. So, as you can see, the right to an independent life is a hot issue in Korea.

Most disabled people in Korea attend special school. But Korean special education doesn't give them opportunities for social activities. So some of them prefer to enter normal school. But people with learning difficulties especially find it hard to get a normal education. Many of them go to vocational school. There are about 200 of these.

But they find it difficult

to get a job because many employers think that we are less productive than nondisabled people. Korea has affirmative action named "Disability Employment Promotion Act". This action says: "All firms which have more than 300 workers must have two per cent disabled people in their workforce. If they don't keep to this quota they have to pay a penalty. But many firms choose to pay the penalty rather than observe the quota.

In 2008 fewer than 1.5 per cent of Korean disabled people were in employment. Furthermore, most disabled people have basic labouring jobs. But those of us who are university graduates aspire to jobs better fitted to our skills.

To sum up, many disabled people in Korea live in poor conditions. Of course, government supports them financially with benefits and tax relief, and creating affirmative action for getting people into employment in the civil service. But this doesn't solve the problems most people face in their lives. If they have family, their poverty becomes worse because they can't make money to feed their family. I think the only real solution is getting jobs for them. This is the key to a better life.

## one2watch

## A cast off no more

Following her triumph as Gabriella in Channel 4's Cast Offs, Sophie Woolley shows she's no one trick pony. With other writing and performing credits to her name, she now tells us why she may have to make a pact with the devil and why she'd like to be Howard Hughes

#### What's the best thing about being Deaf?

I'm on a plane, a baby is crying next to me, I switch off my hearing aids and feel smug. But looking at the bigger picture, I'm far happier now that I'm deaf than I was when I was hearing. So my hearing loss must be doing something right. Thanks genes!

#### What makes you angry?

Check out that Deaf Faker woman (on YouTube). She is so conceited and punch-able. Grr.

#### What is the funniest or strangest thing someone has said to you about your deafness?

I was at a party on Saturday and someone said "how is it for you, being deaf, how does it feel?", which made me laugh out loud in an "oh gawd" sort of way. Then I replied, "It feels lovely, it's going really well".



#### If you were Prime Minister, what one thing would you do to improve life for disabled people?

The cruellest thing happening right now is the proposed cut to mobility allowance. Shame on the Coalition. Shame on them.

#### What do you love most about what you do?

Being the master of my imagination.

#### What do you least like about it?

There is so much I want to do creatively, there simply aren't enough hours in the day. I might have to sell my soul to the devil in exchange for immortality in order to get everything done in time for Armageddon.

#### Who is your favourite disabled person ever and why?

There is only one answer to questions like this and that is always, always Nelson Mandela. I think he wears hearing aids now.

#### If you could do any job in the world, what would it be and why?

I'd like a job as Howard Hughes. He was a filthy rich, American aviator, engineer, industrialist, film producer, director, philanthropist. And deaf.

#### Do you have any special or hidden talents?

I have no hidden talent. It is all manifest.

How would you sum yourself up in ten words or less? Brilliant.

#### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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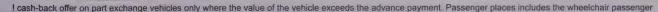
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For many actors, a return booking to play a part they've made their own would look like they'd made it. But **Sunil Peck** discovers that Donna Lavin hopes it's only just the first step on the road to stardom

t's 24 hours before Donna Lavin is due to go into the studio to record the second series of *The Pursuits of Darleen Fyles*, a drama for Radio 4's Woman's Hour daily drama serial.

The production tackles the relationship and employment issues that Darleen, a young woman with learning difficulties, has to deal with on the road to living independently as an adult.

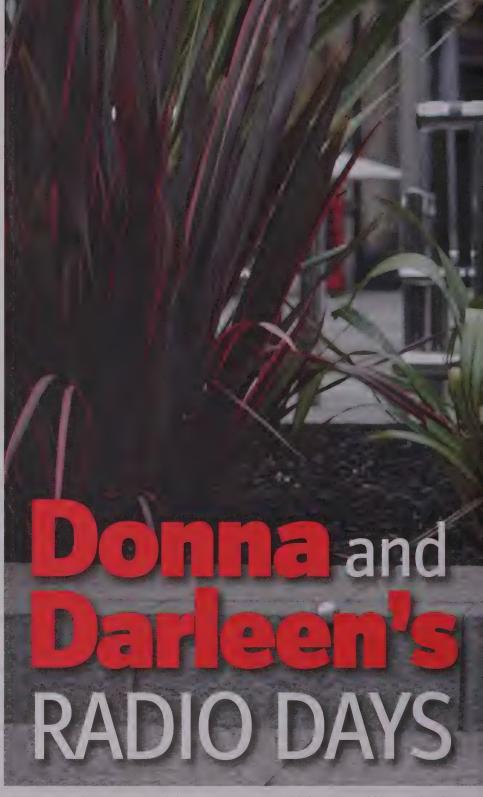
The director tells me that Donna, who has cerebral palsy and learning difficulties, became a cult hero among listeners after the first series was broadcast in 2009. She is due to feature in about 48 out of 50 scenes in the second series so you'd think she'd be nervous.

"I'm used to it now so I'm more relaxed and I know what to expect and I'm not so nervous," says Donna. "Before the first series I'd have sleepless nights, I needed the toilet five times an hour and I couldn't eat anything. But once there, I felt alive!"

Despite the pressure, it's Donna's infectious enthusiasm rather than her nerves which shine through.

"It's exciting, but I suffer terribly from stage fright, it sounds silly. It's because I'm convinced that everyone will laugh at me or point out my mistakes."

The plot, which has covered uncaring service carers, workmates who take advantage of her good nature and her mother's fear of Darleen having sex, is not autobiographical, but Donna, who lived in a care home for four years,



does work with the writer and director to develop the storylines.

"In the second series, Darleen takes driving lessons, and I'm taking driving lessons in real life. But I'm doing a lot better than Darleen does! Darleen gets married too and a few months ago the writer and director asked me what I thought my wedding dress might look

like. I told them I would have a bright red one and it was in the script!"

The drama was adapted for television in 2010. "My mum forced me to watch it," says Donna. "It was awful. I closed my eyes when I came into shot. I think the other actors did a wonderful job."

The Telegraph's TV critic said that



Donna's performance was "terrific".

"I don't think I was, you see yourself differently to how others see you and as an actor I'm too close to it all and I know where I've made a mistake even if the audience don't."

Despite her successful television debut, Donna preferred playing Darleen on the radio which was "not as demanding".

"The radio is very relaxed and chilled out. If you want a break you can have a break, there are bright rooms and you can sit down with your bottle of water. Television was a lot different. There were loads of people running towards me messing with my hair and looking at my face to decide what

There were loads of people running towards me messing with my hair and looking at my face to decide what mascara would look good. At first I couldn't bare it. A girl likes to put her own make-up on

mascara would look good. At first I couldn't bare it. A girl likes to put her own make-up on so it feels a bit weird for someone else to do it. But by the end of filming I was like 'can I have another touch up please?'. I had my own trailer too, it was lovely! But I didn't use it because I didn't get many breaks! We started at about eight o'clock in the morning and finished at seven and it took just over two weeks to film. It was demanding because you could end up doing the same scene five times in one day because it had to be shot from so many different angles. It was draining, but in a good way."

Now 28, Donna's acting career began when she was 19 and studying business administration at college.

An audience member approached her after a play and asked if she fancied auditioning for Mind the Gap, a theatre company for actors with learning difficulties.

"Oh my god, the audition was really embarrassing! We had to do this restaurant scene with a difficult customer. I was running out of excuses and ended up throwing chopsticks at him and saying 'you can use these to eat your pizza'. Then my foot caught on the table leg and I went flying and the table collapsed on top of me. I said 'you don't get out of that one, you still have to pay for your dinner'."

Donna left the audition in tears



thinking she'd blown it, but it was probably her improvisational skills that landed her a job with Mind the Gap.

"They rang me that night to offer me a part! I asked them why they wanted me after such a disastrous audition and they said 'it was a bit of a disaster, but you showed us that you could carry on through it and that's the most important thing'."

In her four years with the company, Donna performed on national tours of Cyrano and Of Mice and Men. The director liked her voice and she was often cast as the narrator.

"You get a lot of lines, more than anyone else. That's what an actor wants but at the end of the day it's more demanding and you get more tired than everyone else. You need more breaks, but you're the one who has to keep it flowing. One of the reasons I left was because I'd worked for four years solid and I had no social

I keep sending my CV to agents but none of them are taking me on. It's hard to go to auditions if you don't know they're on. If you don't have an agent you have to pretty much figure it out yourself

life, I was absolutely knackered."

On her last day at Mind the Gap, Donna met Pauline Harris, a director on the look out for a disabled actor to star in a radio drama.

"Somebody had said to me that I should see Donna so I set up an audition," says Pauline. "I sent her an extract from a play to see how she interpreted it and sight read, and she knocked me out. It was a great reading. I asked her to do some improvisation around some of the ideas we had for the character and she brought life, energy and wit and a quirky dimension to it."

Pauline goes on to talk about an attempted rape scene in a nightclub toilet in the first series of the *Darleen Fyles* which she says illustrates why Donna is such a "bloody good actor".

"We talked about the rawness of it and how to get in touch with those feelings, and then she just did it in the first take."

Donna's gift of being able to act harrowing and more mundane scenes with equal aplomb, and the speed with which she learned to play to a TV camera, has convinced Pauline that Donna would be a great addition to *Coronation Street*.

It's an opportunity Donna likes the sound of too. But despite her acting prowess and the success of the *Darleen Fyles*, she is finding it hard to land other roles. Donna says that it's not

because of prejudice, it's because acting roles are in short supply.

"I keep sending my CV to agents but none of them are taking me on. It's hard to go to auditions if you don't know they're on. If you don't have an agent you have to pretty much figure it out yourself. But if you don't know anybody you're going to miss out. I hope to get more TV work and then I might get somewhere."

If Donna has her way, she'll be playing Darleen for a long time to come. But is she keen to play roles where her character is not defined by her disability?

"It doesn't really matter to me. But my dream role is to be a really bad character who kills her husband or something. I think it would be fun to go home at the end of the day and say



'I've killed someone today or I've robbed a bank today!""

She does rule out any nude scenes because "it gives out the wrong message. I want people to see my shows, not me. I want to be a good role model for disabled people. I want other disabled people to look at me and say 'she did it, so I'm going to'. I think you have to keep an air of respectability about you."

As someone who believes that

aspiring disabled actors ought to have equal opportunities in the mainstream rather than having to rely on companies like Mind the Gap to get a break, Donna is proud to be doing her bit to promote a positive image of disabled people as actors.

Donna dreams about starring as the first disabled person in a blockbuster movie. So does she think she will be living her dream if we happen to bump into each other in another five years?

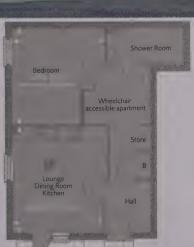
She laughs.

"I shall open the gates to my mansion and let you in, I'll introduce you to my limousine driver and I'll show you my pool, tennis courts and my home cinema room. That's the dream but will it happen? Nobody knows. I'll probably have to go to America to make it on the big screen."



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## CLOSED

It's a tale of hidden and not-so-secret closures, jobs axed or not filled and service users left without the support they rely on. Annie Makoff investigates the hidden agenda behind the Government's mental health strategy

# Organised

Cuts leave lives in crisis

overnment plans for mental health trusts are just smoke and mirrors," says Chaminda Jayanetti, public sector cuts campaigner and activist. Part of the Falseeconomy.com team which officially launched earlier this year, Chaminda has been closely monitoring the full scale of public sector cuts for several months, using Freedom of Information requests and foundation trusts' annual plans. It was through his research for Falseeconomy.com that the real scale of NHS cuts became apparent: 53,150 job losses are expected between now and **2015**. Of this, 6,346 jobs are at risk across 53 mental health services.

"Most trusts gave me their five year plans," he says, "but there is a decent chance that these figures are going to significantly increase over the next few years."

The figures were announced some weeks after the unveiling of the coalition Government's mental health strategy, which pledged £400m to talking therapies with a focus on early intervention.

At the time, the Government's own independent national health adviser, David Richards (since sacked) suggested that the pledged money was not new and actually tapped into an existing NHS budget. Others have voiced concern over the focus on early intervention and short-term talking therapies in the strategy, which would undoubtedly be at the expense of adult mental health services.

We've done nothing but campaign against these closures. I can't express how affected we are by this, they are taking away something that is so important to us

Disability Now has uncovered further evidence which indicates that vital mental health and social care services throughout England and Wales are already experiencing significant cuts.

A mental health social worker who

does not want to be named, told Disability Now that 20 per cent of jobs will go in her Community Mental Health Team (CMHT) and several psychiatric wards were closing.

"They've already closed several adult wards in the area. We were told they were being refurbished but they never re-opened," she says. "And to save more money, unqualified staff are slowly replacing qualified staff, trainee mental health workers are replacing community psychiatric nurses (CPNs) and psychology graduates are replacing nursing posts. They are even downgrading most posts to lower skill levels."

Already the CMHT is massively understaffed and according to our source, some of her team have been told not to see certain service users due to the paper work and expense.

"The picture that I'm giving is not particular to my London borough," she explains. "It is indicative of what is happening everywhere. The reductions, the redundancies, the lowering of skill levels, it's all the same. It means that service users won't be getting the care and support they need, it's going to reach boiling point. But these boiling points are peoples' lives, their lives will be changed completely."

In Leeds, over 200 service users who attend one of three mental health day centres are about to have their world turned upside down. Both the Vale and Stocks Hill Day Centres are due to close despite fierce opposition and campaigning from attendees, staff and local GPs.

Lynn Payler, who set up the Facebook pressure group, Save Leeds Mental Health Services!! has been going to the Vale Day Centre for over two years.

"Before I discovered the Vale, I couldn't have a conversation without crying because I was so anxious. I have severe depression and anxiety and I suffer from panic attacks. But the Vale has been a lifeline for me and so many people."

Lynn and others first found out about the closure by accident because it was posted online. Since then, there have been five suicide attempts and the majority of service users are experiencing severe depressive relapses.

"It's heartbreaking," Lynn says. "The news has absolutely devastated us. Since we found out officially in December, we've done nothing but campaign against these closures. I can't express how affected we are by this, they are taking away something that is so important to us. "

The three centres – known by locals as the "tri-centres" - the Vale Day Centre, Stocks Hill Centre and Lovell Park offer city-wide residents with mental health problems a chance to socialise, take part in activities, get support from staff and peers and go out on trips in the community. As many service users attend three days a week, it is a vital part of their routine and as Lynn explains, attending gives many a sense of purpose to their lives when

Worst hit mental health trusts for job cuts				
Trust	Total job cuts			
North Staffordshire Combined Healthcare NHS Trust	241			
Coventry and Warwickshire Partnership NHS Trust	<b>557</b> .			
Derbyshire Mental Health Services NHS Trust	400			
Mersey Care NHS Trust	646			
Kent and Medway NHS and Social Care Partnership	560			
	With the	anks to falseeconomy.com		

they are otherwise too ill to work.

The smallest centre, Lovell Park is not intended for closure, but is apparently so small that it will not have the space to take on the additional service users from Vale and Stocks Hill.

Lynn who has not worked for 18 years due to a range of complex physical problems, is adamant that the closures will cost the council more in the long run.

They've already closed several adult wards in the area. We were told they were being refurbished but they never re-opened

"It costs around £33 a day to send us to a centre," she insists, "but if we have to go to hospital because we've had a breakdown, it costs over £3,000 a week. How can they justify that?"

According to figures released by Falseeconomy.com, the Leeds Partnership NHS Trust which runs mental health services in the area, is not the worst affected region in England and Wales for mental health service cuts.

Trusts such as Coventry and Warwickshire Partnership, Mersey Care NHS and Derbyshire Mental Health

Services have revealed over 15 per cent of cuts to job posts alone.

Even those areas with "lighter" cuts aren't immune to the drastic actions local authorities are taking in attempts to save money.

Berkshire Healthcare Foundation Trust expect to cut 400 posts within five years and Nottingham Healthcare are intending to cut as many as 700.

Nottingham have also opted to close 130 supported housing projects as part of these council cuts. Two of the axed projects were specifically for women with mental health problems, some of whom have lived there for as long as 17 years.

Staff at the projects have been given just a few weeks to help social workers find alternative placements for the women as well as looking for new jobs themselves.

One of the projects is home to just five women. 15 dedicated staff who work in shifts offer them round-theclock care and support.

One tearful member of staff who has worked at the project for 13 years, has spoken anonymously to Disability Now: "They've given us such short notice. We were sent an email telling us to move the ladies out – it was the first we heard of it. Everyone is so confused, it's chaos. One woman has

been moved to a care home for the 70s. and 80s when she's 35. It's just not right." Another woman was moved to another project of 21 residents, 17 of whom are men. "You can't treat people like that," says the staff member. "They are putting money before people."

Back in London, service user Gemma O'Connor under Camden and Islington NHS Foundation Trust has found that the services she once relied on are no longer available to her. The local crisis team now refuse to step in during a crisis unless a suicide attempt has been made. "It's no longer a preventative measure," Gemma says. "And my psychiatrist told me recently that because of the changes to the NHS, they won't be able to continue treating me. I've even been told I have to pay for my own psychotherapy! I'm on benefits, how can I possibly afford that?"

Gemma's story is not unusual. Even before the cuts, there have been stories of service users having to finance private treatment because of lack of funding.

Sheffield student Leon Kowalski is one such person. Diagnosed with dissociative identity disorder (DID) in 2006, Leon had to fund his own treatment using his DLA because there was no NHS help available. "The treatment for DID is long-term psychotherapy," he explains. "But I was offered just 21 sessions and then discharged, even though I was told my condition was serious. Medication doesn't help DID, so I am viewed as untreatable. They don't know how to treat me so they don't treat me at all."

To add to Leon's concerns, Sheffield recently announced a £1m cut to its

mental health services. "I've been hospitalised and I've had interventions from the police and the crisis team," he says. "But they say they can do nothing. I honestly don't know how the mental health system can cope with any more cuts as it is failing to provide support for people as it is."

It is becoming all too clear that these documented cuts are just the very tip of the iceberg. With many mental health trusts yet to announce their reduction plans and hundreds more services awaiting imminent closures, the future of our vital mental health services looks arim.

London-based Gemma agrees. "It's a scary time," she says. "The mental health system is becoming more unstable by the day: it's a deck of cards."

Some names have been changed.





## yourviews

#### **European Disability Forum fails us**

As a Green Party candidate in May's local elections, I oppose the main parties' approval of "massive cuts to local services" in the nation's effort to "slash spending and cut the deficit".

But I am also concerned that taxpavers' money for the purpose of helping disabled people is being wasted on the European Disability Forum (EDF).

Less developed Eastern European countries have been represented by people promoting outdated methods of dealing with disability. For example, the Slovenian representative to the EDF is Boris Sustarsic. Mr. Sustarsic tries to promote Slovenia as an Eldorado for the disabled and continually attacks organisations supporting aspirations to independent living of disabled people, even in other EU countries.

Kapya Panayotova, from Bulgaria, is co-chair of the European Network on Independent Living (ENIL) and agrees EDF should be abolished. She complains that Bulgaria holds the record in institutionalising disabled people, and children in particular. She is particularly critical of many of EDF's Bulgarian members: traditional



**European Commission in Brussels: Money wasted on the EDF?** 

disability organisations, impairment based, charity oriented and heavily funded by the Bulgarian Government, they receive direct subsidies and then apply for additional funding for special projects.

Her view is that many of these bodies are already quite well off. Their constituency is made up mainly of elderly and inactive people happy to cadge a free dinner, free vacation or just a day or two's excursion to some famous place or social

Millions of euros go into institutional care; research reports have been produced and publicized. The impact has been nil.

I have had a head injury and my wife has spina bifida. The EDF is happy to describe most of us, prejudicially, as "people unable to represent themselves", as if this kind of language can justify the institutionalisation of disabled people.

The EDF is not an organisation that exists to improve the quality of lives of disabled people but to enable organisations for disabled people to enhance their own role and status, even if it is to the detriment of the rest of us.

Tony Kellsall, by email

#### **Autistic guidance**

My son is autistic and I wrote to you in February about the failure of the system to support him.

In short, I educated him at home until the age of six and then again from the age of seven to eight years. During that time he made real progress in all aspects of his educational and social development.

From six to seven and eight to 16 years, however, he attended specialist schools for autistic children, funded at great expense by local authorities. While in the educational system, not only did he fail to progress any further, but in many respects actually regressed.

It is my contention that specialist schools are more like expensive child minding services due to a lack of appropriately skilled staff. I have now been left to pick up the pieces, in order to make up for all my son's lost vears. The challenges I have had to endure in starting a home education programme show that my decision, although absolutely a last resort, is already showing real results after just six months.

I am more than happy to talk to other families in a similar situation, should anyone wish to contact me. Sandy Howarth, London W3



#### Disabled actors can act, actually

I would like to make my views known on actors in Hollyoaks (cover feature Disability Now, April 2011). That only a disabled person with a disability should play a disabled character.

To give an example, the character of Jackson Walsh (played by Marc Silcock) in *Emmerdale* is paralysed from the waist down, as a result of being in a train crash. An able-bodied actor was needed to show how Walsh ended up in his situation. Does that makes sense?

On the other hand. Emmerdale has brought in a character called Steve Kelly,

played by Andy Walker (pictured above), who was paralysed in real life as a result of a diving accident in Goa in 2006. The Back-Up Trust contacted Andy, who'd never acted in his life, but gave it a go. That's more impressive than can be said for Bryan Kirkwood, who dropped Adam Best (played by David Proud) from EastEnders the minute he came on board as producer. Kirkwood used to work on Hollyoaks.

My mum thinks Andy is a hunk. How about having him in your magazine? Alan Fox, by email

#### Where should disability cuts be made? Remploy could be one starting place

I read your online article on welfare cuts ("Hard times ahead") and started to think that, since cuts are inevitable, we need to act pre-emptively, before cuts in essential areas are imposed upon us by others.

Messrs Cameron and his friends in the Big Society project want all of us to be involved in the change. After all, "we're all in this together..."

So who spends the largest chunk of money? Disability Living Allowance (DLA) is being looked at, and disabled people on Incapacity Benefit are moving over to a more strict regime, but what about the state?

In these austere times where every penny counts, should the coalition Government continue to fund Remploy to the tune of over £150 million a year, given that so many social enterprise firms now deliver a similar and possibly better service, and provide a better fit to Cameron's Big Society? It may not be on the same scale, but then they've not had secured funding for a lifetime like Remploy.

If user-led organisations and social enterprises could grasp the opportunity, would there still be a need for such a centralist government-funded body? If so, Remploy could be carved up and allowed to operate on a more flexible basis. (But could Remploy grasp such an opportunity?)

It is a shame that such a large body, with resources to make a significant impact on society, doesn't attempt to be braver in its actions. Instead we only hear of the company when it is either defending itself or making stupid mistakes by insulting its own employees and having to settle the matter at a tribunal.

Such problems occur in all companies, but Remploy gives every indication that, having restructured its business, it hasn't changed its behaviour. It continues to act as if it is looking after or taking care of disabled people, rather than empowering disabled employees to step up and manage its future.

That would be a model worth developing. Graham Hughes, by email

#### → Have your say

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- · email us editor@disabilitynow.org.uk

## mikeoliver

## The fame game and the new elite

Andy Warhol's prescient vision of 15 minutes of fame for everyone has now become reality. But, asks Mike Oliver, at what price and cost

t seems that as a society we value those who amuse, entertain and distract us more than we do those who inform, look after and protect us. A classic example of this is the recent film The Hurt Locker which won numerous awards. Why else do we pay one group of young men who pretend to dismantle bombs more money for a few months "work" than another group of young men will earn in their whole careers for actually dismantling these lethal weapons? Why do we pay footballers more than doctors, pop stars more than teachers, newsreaders more than the police?

More recently everyone is raving about the The King's Speech which is about stuttering in the Royal Family. A very worthy film no doubt but in all the acclaim and rewards it has attracted, I have yet to see anyone point out that many thousands of people are currently being denied

access to much needed speech therapy services. I wonder how many speech therapists could have been employed if the costs and the profits from the film had been used for that end?

We obviously value our entertainment and diversion more than we value our education, health and protection to the point where celebrities have become the new elite. Our media is now crammed with stories about people who are often only famous for being famous and even about those who are only relatives and hangers-on to those who are famous. Since the days of Princess Diana even the Royal Family have joined this new elite. Small wonder many of our young people when they leave school only want to be celebrities, footballers or WAGs.

So where does this rise of celebrity culture leave us as disabled people? In the past many of us have been a source of entertainment and distraction: from the

medieval village idiot through the day trips to the asylums and onto the 19th century freak shows. Now many of our television programmes are becoming modern versions of these freak shows and we see more and more disabled people participating in

Perhaps this is a good thing and we should be pleased that disabled people

We obviously value our entertainment and diversion more than we value our education, health and protection to the point where celebrities have become the new elite. Our media is now crammed with stories about people who are often only famous for being famous

are getting the chance to participate fully in celebrity culture. After all, full inclusion into all aspects of society is what we've been aiming for and we should be pleased that disabled people are enjoying some of the rewards for participating in the diversion and entertainment industries. I don't criticise individuals for doing this but I would wish to point out that there is a price to pay for entertainment and diversion.

Over the next few years the new elite will not be asked to pay the price for the recent failures of our global financial systems but one of the groups who will is disabled people. Our standards of living, our lifestyles and even our lives may be at stake in this and we face a difficult choice. We can be entertained and distracted through this economic catastrophy or we can try to understand what's really happening so that we can do something about it.

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#### **Property KATE SHEEHAN**

Director, OT Practice, with special interest in housing

#### **Motoring and Transport HELEN DOLPHIN**

A director of Disabled Motoring UK (formerly Mobilise)

### How will the new carer's room allowance work?

I am writing to enquire about the new carer's room allowance announced in the last spending review. Is there any confirmation that this new allowance exists? I would very much appreciate some quidance.

Rachel Ramsay, by email



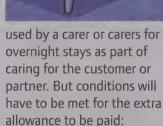
#### Kate Sheehan replies:

There are two principal pieces

of legislation on this issue. One, the HB/CTB Circular A25/2010, provides guidance on the Housing Benefits (Amendment) regulations 2010. The other, the Rent Officers (Housing Benefit Functions) Amendment Order 2010, gives clear guidance on the provision of funding for a non-resident carer's room.

From 1 April 2011, the new provision will permit the Housing Benefit assessment to include an extra bedroom for tenants in the private rented sector who have care provided by someone who lives elsewhere.

This will apply where a customer or customer's partner needs overnight care and already has an additional bedroom that is



- •The customer must be a tenant in the private rented
- •The carer may not live in the tenant's property but only stay overnight for the purpose of providing care
- ·Only one extra room is allowed
- · A spare bedroom exists that can be used by a carer or team of carers for

overnight stays

•The overnight care is only provided for the customer or partner and not for other members of the household. e.g. children or elderly relatives living with tenant.

In order to establish if an extra bedroom can be included in the assessment. local authorities will need to be satisfied that:

- · Overnight care is in fact required
- The care is in fact provided on a regular basis
- · A bedroom is available for the carer's use.



#### Why don't councils simply enforce parking law?

In Oxfordshire. where we live, the local council isn't challenging people who use disabled bays outside control times, and traffic wardens don't seem to check Blue Badges. Instead, they've gone to the expense of installing pay points that are so close to the ground that it's hard for able-bodied drivers to use them - an ingenious but expensive ruse. I also read in your magazine that a new badge is to be issued which will be more difficult to forge. Wouldn't it be a better use of money just to enforce the law? I don't even mind able-bodied people using disabled bays, as long as disabled people pay less. Alice Pike, by email



#### **Helen Dolphin** of Disabled **Motoring UK** says:

Most councils outside London seem not to enforce the use of Blue Badges, which is why levels of abuse of the scheme are cited at around 50 per cent. I'd suggest you write to your MP and ask why preventing Blue Badge abuse is not a priority for your authority.

Recent statistics have shown that local authorities are losing £45 million in lost



parking revenue through misuse of the scheme, so there's not only a moral reason to do something but a good business case.

I agree that if a council introduces charges for using its car parks there should be a reduced fee for disabled people, taking into account the additional time taken to load equipment, get around the city, take rest breaks, etc.

As you would have read in Disability Now I successfully used the Equality Act 2010 to get my local authority to change its parking policy to allow Blue Badge holders double the amount of time for the same amount of money. I actually think it should be free of charge, to discourage Blue Badge holders from parking on the street, which is less safe and more likely to cause traffic congestion. The solicitor I used was Martin Harvey at

Wake Smith & Tofields, You can contact him on 0114 266 6660 or email martin. harvey@wake-smith.com if you want to take a case against your council.

Your council is obviously trying to meet the needs of disabled people by putting in low-level machines but that doesn't help people with disabilities that affect their upper limbs so I hope it has a policy to enable drivers like these to park. As for the new style Blue Badge, it's going to make it help prevent tampering and forgery but, as you say, only by badges being physically checked will it stop people using badges that don't belong to them.

#### Lose DLA, lose car?

I have just read Neil Coyle's article about DLA (Disability Living Allowance) on page 39 of Disability Now (April 2011). The guestion this raises is: if I am assessed and lose my DLA (which was awarded for life), would I have to give up my car, or would DLA have to honour the three-year contract with my dealer?

Phil McKuhen, by email

#### **Helen Dolphin adds:**

If you currently do not get your DLA award renewed and have a Motability vehicle, then you have to return it to Motability. Customers are usually given around three months between the cancellation of the allowance and the return-by date, during which the lease can be paid privately, so that there is time available to arrange an alternative car.

I expect this is exactly what will happen when people who are currently on DLA are reassessed as not eligible for PIP. It therefore seems unlikely that any contract would be honoured.

#### → If you have a question for our panel

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### pete'splace

### **Ticket barrier**



Olympics fans won't have to be guizzed about their disability to get tickets. Good news? Peter White's not certain

he word "special" has always caused trouble in the disability lexicon, especially since "inclusion" became an article of faith.

Special schools, special educational needs, special weeks designed to raise awareness - it all smacks of separatism, and a failure to treat us as normal.

The problem comes when "additional" provision is needed to gain fairness and equality. Then what?

The latest tangle involves LOCOG (the London Organising Committee of the Olympic and Paralympic Games), with its arrangements for providing tickets for disabled spectators who want to watch the games.

The "two-for-one" formula is quite well known in sports and arts events: you buy a ticket, and if you need someone to assist you either to get around or enjoy the performance, you get their ticket free. This, you could argue, is "special" provision and, up to a point, it's what's happening at the Olympics. If you're a wheelchair-user you need not a seat but a space, and a seat beside

you for your personal assistant; and that's being done on the two-for-one basis. So far, so good!

But as far as someone with any other kind of disability is concerned, sight-, hearing- or learningrelated, the organisers are making a virtue of the fact that there's no "special" (and by implication, demeaning) provision, no special phonelines, and no special questioning about

the nature of your disability. That, apparently, is a virtue.

But there's a snag. Getting an Olympic ticket, as we all know, is a gamble. You make your application, selecting the events you want to see and the price you're prepared to pay, and then hold your breath! Fair enough; same for everyone.

Except it isn't, because if you're disabled and want a free ticket for your assistant, you have to gamble twice, first for your own ticket, and then for the fact that there'll be a second ticket at that event, on that day.

And given the prices of some of these tickets (let's gloss over for a moment the thousands of seats being

allocated to local councils and sponsors, etc) this is a big gamble.

What's the answer? Some think it would have been fairer to have a fixed allocation of tickets for disabled people and their assistants, regardless of disability, with everyone applying on an equal footing. But, if you did that, it would come under the evil umbrella of "special" provision. The problem is, of course, that "special" provision costs money, and that when people spend money, they want to know, especially now, that it's going to the "right people". Do you know what? I'm glad I don't have to solve this one.



### guestcolumn



Most observers agree that disabled people are being hit hard by cuts but members of WinVisible, writing here, argue that women are being hit even harder

isabled women are facing the worst impoverishment since 1945, through an avalanche of cuts to benefits, housing, and care services, as well as the hike in VAT, privatisation, and the cost of living.

Like other women, we find ourselves serving as unwaged carers for children. partners and relatives, while coping with our own disabilities, all of which is tantamount to work.

Income Support and Carer's Allowance recognise that mothers and other carers are not unemployed, but like incapacity benefits based on need, they are being phased out.

Welfare "reform," led first

by Yvette Cooper for Labour and now by Jain Duncan Smith for the ConDems, is forcing almost every claimant of working age to seek work or lose benefit, undermining women's and children's protection against total dependence and abuse.

Asylum seekers, including survivors of rape and other tortures, were the first to be made destitute: now others are too.

Most single mothers do waged work. Of those who don't, most have a disabled child, or health problem themselves. Work-focussed interviews are compulsory even for full-time carers. Homeless victims of domestic violence, women undergoing chemotherapy,

and traumatised refugee women are pressured into iob-seeking or "pathways to work" interviews, without any recognition of what they go through just to survive.

Attacks on the welfare state and multiculturalism encourage some staff to vent their racism and other prejudices. Most people on **Employment and Support** Allowance (ESA) face compulsory "preparation for work". Aggressive back-towork schemes are prioritised over the finding of suitable jobs. Those rejected by employers are made to "work for their benefits" around £1.64 per hour. What an attack on the minimum wage!

But protests are growing. In January, angry disabled people picketed the London headquarters of Atos Healthcare, paid £80 million per year to carry out benefit examinations. Atos finds 39 per cent of ESA claimants fit for work. June Mitchell was one who was scored zero points while suffering from terminal lung cancer.

In March, 244 MPs voted that the Welfare Reform Bill should not go ahead while replacements are unclear. Though the Government's

majority prevailed, the dispute continues.

After a lifetime of work, most of those who use care services are women pensioners. In January, scores of pensioners protested in Camden, north London, against day centre closures that would leave them isolated at home. Lily Chitty, aged 99, was among them. She has since died.

In February, London's Euston Road was peacefully blockaded while the Council voted in cuts and increased charges. Some protesters held placards remembering Jennyfer Spencer's death at her inaccessible flat a year ago, after Camden stopped her care payments. A muchloved former teacher who became a wheelchair-user following a stroke, she spent seven years trying to be rehoused.

Disabled women were part of the Mothers March on 12 March, called by the Global Women's Strike, and the TUC march on 26 March. Chants of: "We've had enough!", "Welfare not Warfare" and "Homecare cuts are killing us!" showed the determination to call off the cuts: our survival depends upon it. Contact winvisible.org

#### → Have your say

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### upclose&personal

### Being judged by appearance

For many, it's an all-too-familiar accusation: "You're not as disabled as you let on". Anoushka Alexander reflects on other people's judgements and assumptions

was shaking by the time I hung up. The last person I expected to accuse me of "not being ill" was my pharmacist. I had rung to ask about his prescription delivery service, only to be told that he would no longer deliver to me because "you are young and can collect them vourself." His service was not for "people like you". To him serious disability had a certain "look" and I don't have it.

I don't know who the "people like you" are. Lazy people? Scroungers? Or people who have been almost entirely bedridden for seven years, like me?

I shouldn't have been surprised. Since my midtwenties I have had a rare. incurable neurological condition which leaves me in constant and usually excruciating pain, but you can't see it. And people don't see me on a normal day - if they see me it will be on a rare day when I am actually up, however briefly, even if this only means sitting downstairs for a bit.

Even friends find it hard to understand. I remember



a close friend getting annoyed when I rang yet again to cancel seeing her. I hadn't been ill for long then and she thought I was just being flaky. I remember how guilty and judged I felt - although I wasn't actually doing anything wrong.

It is hard for people to grasp the fact that someone really can be young and debilitated by constant pain. It isn't fair - it is just random. It is almost too scary for people to accept that sometimes bad stuff happens arbitrarily, because if they accept it happened

I don't know who the 'people like you' are. Lazy people? **Scroungers? Or** people who have been almost entirely bedridden for seven years, like me?

to me, they will have to accept that it could happen to them.

The problem is more serious when it comes to benefit assessments,

because if I am well enough to get the assessment it is by definition a good day and I will not look that ill. This is no doubt why I failed my first assessment and had to go to tribunal to get my benefits reinstated. What the assessors don't see is that all the times when I can't turn up I am scrunched up in agony in bed. Or that when I get home from the assessment I will be straight back to bed and a handful of heavy-duty painkillers. I am grateful I now have a concrete diagnosis, and a matching set of hard core medication to "prove" I am ill. But even that was not enough for my pharmacist.

I am sure it is the constant rhetoric about benefit scroungers which feeds this prejudice. I have yet to meet anyone who is pretending to be ill or disabled to get a meagre income from the state. As I told my pharmacist: life is difficult enough when you are disabled, without having people make assumptions about you.

v wedding dav was the best day of my life. I always wanted to get married, especially after I met the wonderful Diane. Having said that, neither of us wanted to throw money at our big day. With sums of £20,000 guoted as the cost of an average wedding, I hope that my tips might help you get the day of your dreams without putting you in penury.

Where to begin? Picking a date. Don't always rush towards a summer wedding. The summer no longer promises nice weather and it costs more. Pick a time of year that means something to you, but try to be flexible. We picked November 5th. because it meant there would always be fireworks on our anniversary.

Next is venue, both for the ceremony and the reception. Nowadays you can do the whole thing in one place, which is a great idea if access is an issue. Make sure you test out any potential venues and that your venues are available on your wedding date! Try somewhere different. We used a local canal museum, which had great access and caused everyone to comment on how great a venue it was. So think places of local interest.

Once you have the date and venue, the next biggie is The Dress. I think the outfits of the bride and the groom are equally important, so let's deal with them together. Go simple and custom. Whatever your disability, having your wedding outfit made to fit you makes you feel great. My wife made her own dress, and looked amazing. The current fashion in dresses are for simple lines, with flared A-line silhouette. Suits are single breasted, and it's very now to wear a waistcoat, thanks to The Mentalist's Simon Baker.

Now we need to sort the entertainment. I programmed up my



With talk of weddings everywhere at the minute, Mik Scarlet chimes in with the zeitgeist and offers a free wedding planner service for anyone thinking about tying the knot in the future

laptop with a night's worth of favourite mp3s, put it through my stereo set-up and pushed play, but I expect some of you would prefer something a bit more grand. All I would say is it needs to be fun.

The cake is another key ingredient, if you excuse the pun. Think local and personal taste. Who likes fruit cake anyway? A good friend of ours plumped for cup cakes, we had a double tier Victoria sponge. I was still eating it weeks afterwards. Then there is booze and food. We got all of our drinkies on a sale or return basis and had veggie only finger food. Our relatives complained

about the lack of meat beforehand, but fell on it like locusts.

I designed all the invites myself, using standard publishing software. I printed them on nice paper and they looked super professional, even if I say so myself. Don't forget to include the important information, like the date, directions to the venue and ask for a RSVP.

As for photographs, get in a professional if you can afford it, but in a world where digital cameras are even on phones, if you like you can rely on relatives. Maybe run a competition for the best piccies?

So with the wedding pretty sorted

(don't forget the rings!), let's do the honeymoon. A major part of your experience, the honeymoon tends to be one of the biggest expenses. We spent a week in our favourite accessible city. Barcelona, but there are some beautiful and accessible areas here in the UK. Penzance in Cornwall is a personal fave.

Lastly, rely on your best man and maid of honour. Get them involved early on, and trust them to help you if you need it. Don't try to run the whole event yourselves. We did, and while it saved money, it did cause a few moments of drama.

All of this might seem a bit obvious. but if you box clever you can have a superb day without breaking the bank. We did it all for under £5,000, including honeymoon.

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DRESS PATTERNS: weddings.lovetoknow.com/wiki/Wedding\_Dress\_Pattern: www.marfy.it/eng/activenews.asp

CUSTOM RINGS (where I got mine): thegreat froglondon.com

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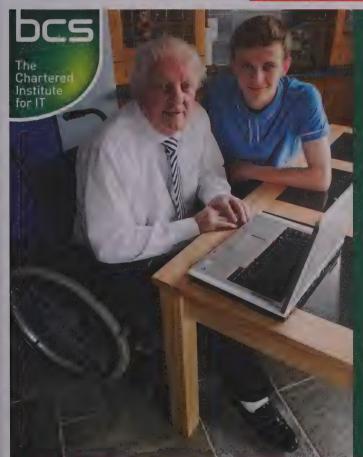
HONEYMOON: Cornwall: Scarlet Hotel - award winning accessible hotel with cool name - scarlethotel.co.uk

Queens Hotel (our favourite) - queens-notel.com

Barcelona: Whotelis Apartments, not super accessible but really swish whotells.com/es

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# After the Gold Rush

Arctic rain forest, ice cliffs and fjords, bears, bald eagles, reindeer sausage and the dying memories of gold fever. All encountered by Marion Bull on her trip beyond America's last frontier

ooking out to sea over the Cook Inlet with jet lag, it feels like the freshest air you can ever breathe, but even in mid-September the north wind is starting to bite. I wandered off past a few Tlingit wooden carvings outside Anchorage's tourist shops for a lunch of clam chowder, but to me and my jetlag it was still only 2am.

The inlet is named after Captain Cook who searched for a sea route in 1778 – the Inside Passage – that would link the Pacific and the Atlantic.

The Last Frontier, as Alaska is known in the States, is a vast pristine wilderness of glaciers, massive ice fields and a sprinkling of towns, some so far apart that the locals really are pleased to see you. Because of the terrain - some of the ice fields, up to 40 miles across, resemble giant tubs of ice cream marbled with sauce - many places are only reached by air.

Glacier Bay seemed a good place to start. I flew from Anchorage to Juneau



**Skagway Broadway** 

and then to Gustavus, a small village with an airstrip in the middle of nowhere. Near the entrance to the Bay, I strolled through Arctic rainforest of spruce and hemlock. The trees are festooned with moss that hangs from

the branches like teddy bears, but I didn't like any of the advice I'd been given about finding a real one. "Don't run", "play dead", "back off slowly", or even "ring a bell" (you can buy bear bells in Anchorage shops, but that was a long way off by now). It seemed safer to view them from a boat.

The entrance to the Bay is at Bartlett Cove, where daily tour boats take you to some 16 tidewater glaciers that didn't exist 200 years ago. Early explorers were met by a wall of blue pack ice, with a 15,000ft backdrop of Mount Fairweather. With phenomenal glacial retreat, finger-like fjords appeared, and you can sail round them to view spectacular wildlife. A flock of terns hitched a ride on a passing ice floe as I watched, a humpback whale left a geyser of spray in the distance, and a pair of bald eagles circled overhead, while seals flopped over the rocks. A young brown bear did appear, but only briefly, sniffing around the shoreline.

The light is painful. Water, sky, and ice



Clockwise from top: Malaspina Icefield; Glacier Bay entrance; Gustavus; Arctic rainforest, Gustavus







combine to make a continually changing show of reflections. Suddenly the sea dipped to accommodate a glacier's snout that broke away with a terrible boom into the meltwater, in a dynamic powdery explosion, leaving natural ice sculptures in its wake. It's known as White Thunder. Large icebergs have been known to carry off bridges, or even whole buildings along the coast.

Suddenly a mist descended over some of the glaciers, and it was time to head back. Not sure where to go next, I asked one of the locals whether I should get a small plane to Skagway (described by one 19th century visiting Mountie as "little better than hell on earth") or go to Juneau. "Oh, Juneau. It's nicer," she said. So I got on the plane to Skagway, late afternoon, the only passenger. although it did have two can-can dancers painted on the fuselage.

Skagway, meaning "Spirit of the Cruel Wind" in Tlingit language, is the most northerly point of the Inside Passage. I'd flown over the crusty tops of glaciers at sunset to get here. There was only one road out, leading north to Whitehorse. across the Canadian border.

Skagway's main street, Broadway, with its historical building facades and the Red Onion Saloon (a former bordello) is like stepping back into the Wild West, except that the entire town sprang up almost overnight to accommodate treasure seekers during the Gold Rush. Amazingly it was Alaska's biggest town then, but nowadays it's little more than a village, apart from in summer when it's the most popular port of call on Alaskan cruises. Most of the town's carefully restored buildings, boardwalks, and stores boasting reindeer sausage and moose milk are accessible.

I stayed in Skagway's Home Hostel, where I had a glacier view. Next morning, an amazing natural phenomenon occurred, that



In the morning at Skagway

sometimes happens on clear days. It takes so long for the sun to reach this little town (there is a 7,000ft mountain to climb), that when it does, the whole place steams and smokes as though the valley were on fire, and in the fields Alaskan fireweed glows red.

Everywhere there are references to the Gold Rush. Prospectors left from here via the White Pass, or from nearby Dyea - now a ghost town, struggling on foot up the Chilcoot Trail, to get to the Yukon. Skagway's most famous roque of the time, Jefferson "Soapy" Smith, conned gullible newcomers out of \$5 apiece for telegraph messages home. What no one knew was that there was no telegraph office here, and the wires in the wall led nowhere. He died in a shoot-out, aged 38, and is buried in Skagway's Gold Rush cemetery.

Only half of the 60,000 who set off in the winter of 1897 actually made it to the Yukon. Many were killed in an avalanche. 3,000 abandoned horses littered the trail in an area that became known as Death Horse Creek. By 1900 when the White Pass railroad was completed, it was too late - the Gold Rush had ended. Nowadays the accessible narrow railway is used to

transport tourists through some of the most fantastic scenery on day trips from Skagway to Canada's Yukon Territory. There are wheelchair lifts on each side of most trains.

It seems as though the early prospectors paved the way for the tourists to have an easy time. But what drove them to take on such a trip in the first place? It may have been greed – but no one made any money. For many - and they came from all walks of life, from waiters to solicitors – it was a voyage of self-discovery. For the first time, an opportunity to experience nature at its most raw. Perhaps this is why the toughest had no desire to return home.

But taking in the panorama around Skagway, even in the face of the north wind, I like to think that some of them stayed on to admire the view.

#### Information

Compare flights from UK to Anchorage: cheapflights.co.uk

Further information:

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### tried&tested

### First bite of the apple

Making the switch from a PC to an Apple Mac computer seems to be a bit of a trend among disabled people. Sunil Peck was a cynic; now he's seen the light



or months I've been loathe to ditch my Windows PC and switch to an Apple Mac. It wasn't just those Apple bores who bang on about how superior Apple is to PCs that put me off, it was the amount of time I knew it would take to learn to use a new set of programs and keyboard commands.

But following a series of sudden crashes and a letter asking for a £200 upgrade fee for my Windows screen-reading software, I decided enough was enough.

Several weeks on, and my only regret is that I

didn't do it sooner. It'll be a while before I get near the level of proficiency I reached as a PC user over 12 years: it took me two days just to get through the initial configuration with the Mac's built-in screen reader VoiceOver, which everyone else seems to find dead easy.

And yet, two weeks on, I'm surprised at how comfortable I now feel using email and Twitter and surfing the web.

That's a lot to do with the many hours I spent fiddling around in various applications and pressing key combinations just to see what would happen.

I'm also indebted to the blind Mac users who give unpaid tech support on email forums and record audio tutorials on accessing the Mac from the keyboard.

Alex Barker, Advice and Information Officer at the charity AbilityNet and a Mac user for four years, tells me that Apple has also incorporated assistive technology into the Mac's operating system for people unable to use the keyboard mouse or trackpad and who are partially sighted.

But he also says that, not surprisingly, there are still far more third-party solutions for people with other disabilities available

for Windows compared to the Mac.

"I do a lot of work with people with motor neurone disease who use a package which is a switch-operated system to communicate and control your computer. At the moment, there's nothing like it available for the Mac. But that's not to say there won't be in the future."

From my point of view, Apple has to address the fact that I don't know if an application is accessible with VoiceOver until I've bought and installed it. I bought an app from the App Store because it was completely accessible on my iPhone. But it doesn't work on the MacBook.

But all credit to Apple, a mainstream company, for including a screen reader in its operating system. Although I struggled to get up and running at first, I'm not aware of any other blind user who did.

My advice to anyone thinking of making the switch is not to wait until your Windows PC falls down before you do it. Apart from anything else, it's incredibly reassuring to know that you can revert to your PC if there's anything you're finding hard to do when you first start off with the Mac.

### helendolphin



### Paying for a lack of choice



With fuel-price inflation rife, the cost of motoring hits particularly hard those disabled people who have no choice but to own and drive a car. So does Helen Dolphin find any comfort from recent budget announcements

ike many disabled people my car is my main form of transport. It is difficult for me to use public transport independently and even if I wanted to come to work by bus there is no bus route. Trains don't fare much better as my nearest railway station has lots of steps and no lift.

Because I use my car a lot I decided when I got my latest Motability vehicle that I would get the smallest car possible that would carry me, my wheelchair and my assistance dog. It is not as easy for me to get in and out as the MPVs I've had previously but it's my way of saving money on fuel.

This is now a decision I'm glad I made as it seems every time I drive past the petrol station at the end of my road the price of fuel has gone up. Sometimes it increases between my going to work and coming home. It doesn't seem that long ago that I was bemoaning the fact that the price of a litre had gone over a £1.

Now I'm wishing it was only a pound instead of the £1.39 per litre I paid recently for my diesel.

When George Osborne announced this year's budget the only part that really interested me was the price of fuel. I think some months I now spend more on fuel for my car than anything else. I was

therefore pleased to hear that fuel duty would be cut by 1p a litre and the planned rise which would have added around 5p to the cost of a litre of fuel has been delayed.

It was also announced that the fuel duty escalator that adds an extra penny on top of inflation every vear will be cancelled. Instead a "fair fuel stabiliser" is to be introduced and this will be funded by an increased levy on oil and gas production.

At present, roughly 60

per cent of the price we pay at the pumps is tax. In the future, fuel duty will increase in line with the Retail Price Index (RPI) measure of inflation when oil prices are high. But in vears when crude falls below a set trigger price for a sustained period. the Government will increase fuel duty by RPI plus 1p per litre.

This all sounded like good news but will it mean cheaper fuel? RAC motoring strategist Adrian Tink said: "The fair fuel stabiliser will mean in the

It seems every time I drive past the petrol station at the end of my road the price of fuel has gone up. Sometimes it increases between my going to work and coming home

short term an end to the above inflationary (extra penny) part of fuel duty increases – that's the good news. The bad news is that drivers will still be hit with a delayed 3p per litre

inflationary rise in January and the prices at the pumps will still be at the mercy of oil prices and energy companies."

With fuel companies quick to blame the wake of political unrest in the Middle East and North Africa for the sharp increase in global crude oil prices we could still be looking at soaring fuel prices. This is not good news for those of us who have no choice but to use our cars and some concession still needs to be made for disabled motorists.





### DOM By Paul Carter



### Home games bring golden hopes

In the first of a series of interview profiles with GB medal hopefuls in the run-up to the 2012 Paralympics in London, Paul Carter speaks to swimmer Fran Williamson about her hopes and expectations ahead of her third Paralympic Games

With six Paralympic medals already to her name, Fran Williamson is one of the leading lights of the GB swimming squad going into the Games in London next year. After picking up three silvers and a bronze in Athens in 2004, followed by a silver and bronze in Beijing four years later, the 25-yearold is aiming to go one step further and claim a gold.

Having already experienced two previous Paralympics, how does she feel about the prospect of competing in London?

"I'm both excited and nervous about competing in front of a home crowd," she says.

"Racing at any Paralympics, representing Britain, is an honour and a once in a life time opportunity. However, I think London will be electric, knowing Britain will be there cheering us on.

"London, if I am lucky enough to be selected, will be my third Paralympics so I am well aware of how different each Games can be. This, in itself, is exciting as the amazing feelings you get when getting to a Games are always a surprise."

Asked about her own personal aspirations ahead of London, Fran says that while aiming for gold is always the ultimate target, performing on home soil will be just as rewarding.

She says: "Realistically,

competing for my country at home will be the ultimate honour and highlight of my long career. Therefore, putting myself in the position whereby I may be able to gain a medal or two would be phenomenal."

Fran swims in the S3 category, where competition is traditionally fierce. Who does she think her main rivals are likely to be?

"I expect Yip Pin Xiu of Singapore and Patrica Valle of Mexico to give me a great race. However, there are always newcomers or unknowns that can shock the world at the Paralympics.

"We [Great Britain] had a great world champs last year and are currently looking to push that forward into the European champs this summer. We're in a great position as we have several young and talented swimmers moving into the squad, who are looking good to take on the world. Not to mention some senior swimmers who continue to prove their excellence."

For many athletes, one of the most exciting aspects of having the Paralympics here at home, aside from the rare chance of competing in front of a home crowd, is the opportunity it provides to educate and inform people's opinions of disability and disability sport.

Fran hopes that added to this, the legacy of the 2012 Games will be one that inspires other disabled people to get involved in sport and become the future generation of GB Paralympians.

"Certainly, if the Paralympics get the coverage and attention they deserve, it would be difficult for them not to make an impact on attitudes surrounding

HONDA

disability. Hopefully this will be true, not just for nondisabled people, but actually disabled people themselves. London 2012 will help to raise the profile of Paralympic sport, therefore, it will hopefully encourage more people to test themselves and take up a sport to see if they can achieve great things too.

"I, personally, am currently working closely with local and national businesses and charities in order to raise awareness prior to the Games in the hope that this will enhance the Paralympic profile further."



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### entertainmentnow

THEATRE



## You must be jesting

Historic Hampton Court Palace played host to a show which gave a new twist to "Playing the fool". **Michael Shamash** reports

he role of the disabled performer can be a contentious one.

There is the discussion about the authenticity of the performers; can disabled people be played by the non-disabled? Do we just watch reverentially or can we engage critically? We're unused to seeing a disabled performer have a leading role on the stage and our responses mirror our unease.

Yet, this was not always so, as a production that took place recently at the Palace in Hampton Court has made very apparent. All the King's Fools performed by a group of actors with learning disabilities under the guidance of Peet Cooper, a professional jester, aims to chronicle the central place people with learning disabilities played in the court of Tudor England and on the stage.

Peet realised that there was clearly an unwritten history of the role of the fool and jester waiting to be reclaimed. The fool had a pre-eminent role, both providing entertainment to the monarch but also acting as a commentary on the foibles of the time. He wanted to dispel the idea that people with learning disabilities existed somewhere between humanity and pets.

He worked with a variety of theatre companies for people with learning disabilities namely The Misfits and Firebird Theatre: Mind the Gap in Bradford, the Lawn Mowers in Gateshead and the Strathcona Company in London. He organised a series of workshops with participants exploring the themes that emerged and how they could be realised in

performance.

From this initial exploration of the themes that would emerge in the actual performance, a group of the players then went to Hampton Court to see for themselves the backdrop of this history and to try on costumes of the Tudor era. With this knowledge Peet and the performers would develop the gist of the commissioned piece.

There was a supposed subdivision between natural fools who did have a learning disability and artificial fools who feigned intellectual impairment for purely comic intent \*\*\*

Major assistance in examining the historical reality of life for people with learning disabilities was provided by Dr. Suzannah Lipscomb, the research curator at Hampton Court. She ferreted through state papers, records of the Privy Purse, wardrobe records and literature of the time to try and uncover a true picture.

The prime example of the fool was Will Somers. who was also a confidante of King Henry VIII.

There was a supposed sub-division between natural fools who did have a learning disability and artificial fools who feigned intellectual impairment for purely comic intent. Will Somers. it became clear, was a natural fool.

He had a keeper, a forerunner of support staff and had a budget to provide him with clothes of a high quality. What Suzannah wants to emerge from the performance is to disprove the idea that the wit and wisdoms of the fools and people with learning disability is a myth and that the repartee of someone like Will Somers was beyond the ability of people with learning disabilities.

When I spoke to Suzannah, she felt that whilst contemporary labelling can be useful in defining the level of impairment and disability it can also act as a means of sidelining people. In Tudor times people who were different were felt to have a special connection to the divine and consequently were worthy of respect. It is a kind of pre-modern concept of diversity. She

made it very clear that she was not presenting some bygone rose-tinted utopia for people with learning difficulties but equally to suggest that the past was unequivocally awful is incorrect.

Suzannah would like the performance to highlight more positive aspects of the past history of disabled people in Britain and simultaneously to show the skills and attributes of contemporary actors with learning disabilities. She organised trips with the participants to the British Library to examine the written evidence of the time and this has made the history of this period fly off the page.

From this has emerged a vivid and different piece of drama based on researched material from the time. The exciting performance breaks from the lute playing or jousting that makes up so much heritage performance. Learning disabled performers give a sophisticated depiction of this era and an audience is given an opportunity to engage with the world of the learning disabled past and present.

#### **Up-to-the-minute listings**

For all the latest arts listings visit www.disabilitynow.org.uk/entertainment/arts

#### FILM



### Benda Bilili! - the movie

#### **Directors: Renaud Barret** and Florent de la Tullave

Wim Wenders' film documentary account of the emergence and development of the Buena Vista social club - a collection of ageing Cuban caballeros - contributed in no small part to the group's becoming genre leaders in "world music" towards the end of the last century.

The question is, can this film which follows in that music doc tradition achieve similar results for a group of African disabled musos?

You might remember Disability Now grilling this band of disabled Congolese musicians way back in 2009, when they were still

relatively unknown to European audiences. Since then, they have fast picked up a reputation for being one of the liveliest, most unique African exports to grace our shores. They headlined at world music festival WOMAD in 2010, played sold out shows across the UK, Europe and Japan, and quickly became a championing force, a fantastic and shining example of achievement: if five middle-aged men with polio, who have lived a life sleeping on cardboard on the streets, can have the career of their dreams, then why the hell can't anyone

Now they're back with a

beautifully realised documentary charting the band's painfully troubled album-making process and subsequent rise to success. From the streets, where they sold cigarettes and performed for passers-by for a little change to feed their families, to Europe, where they stay in hotels with televisions and heating, meet ambassadors and have fans queue for photos and autographs... seeing life "before the stage", it is hard to believe anyone else could be more deserving.

Filmed by French documentary-makers Renaud Barret and Florent de la Tullaye over a period of five years, the film really

reflects on how difficult it is to start something great from nothing, but that belief in your craft can drive success. For Staff Benda Bilili, all too often it seems like an impossible dream: the band finds. and subsequently misplaces, a 12-year-old satongé-playing genius, lose everything they own in a massive fire, have no money to record songs and are confronted by continuous disbelief from family and friends. It takes five years for them to be able to hold a disc in their hands and call it an album. But throughout, no matter the trouble they find themselves in, they power on, driven by the self-belief that they could do something great. As illustrated by the title of their debut album (Trés, Trés Fort), they are unfathomably strong, and seeing that through the documentary, it's impossible not to fall in love with their passion and craft.

- · Benda Bilili! the film premiered at Cannes and London Film Festival in 2010 and went on general release in UK cinemas in March. It is available now on DVD in all good stores. · · Staff Benda Bilili tour
- the UK in May. For dates visit bendabilili.co.uk

**Cathy Reay** 

#### Motability



#### Mobility equipment



Access and inclusion



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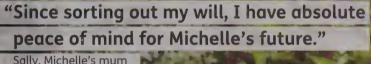


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Vic Young

### webwatch

### Log on, check in, hang out

Forget frustrations over stages without ramps. Sunil Peck finds a venue where anyone who cares to listen can hear musicians performing

usicians and artists who find gigging hard because of inaccessible venues can now take their work to a virtual venue for disabled performers.

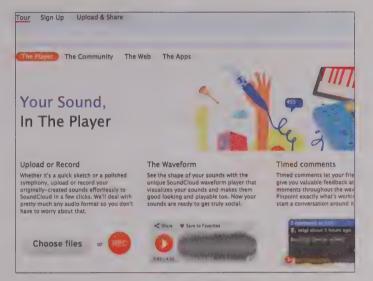
Disabled Musicians Direct has been set up on SoundCloud, an online community for musicians and poets.

"I've been a musician for many years" says Keith Armstrong, who set the forum up. He remembers the 1960s when disabled performers had to be lifted on and off stage by crane.

"Front-of-house access has got better, but things haven't improved much backstage. So Disabled Musicians Direct is for people who have a talent but don't have the means to share their work."

Keith used to make a living performing music but had to pack it in because he was finding it increasingly difficult to get on stage to perform.

Disabled Musicians Direct currently has 40 members, five of whom



had uploaded material.

The uploading process is straightforward, Keith says.

"There are some brilliant songs from Frankie Armstrong, a folk singer, and Elaine Kolb, a disability rights singer in the USA."

Performers can upload up to two hours' worth of material and can choose whether or not it's made available for download.

I decided not to upload the rendition of Sinatra's New York, New York that I sing in the bath, but I had no problems browsing, playing and downloading an eclectic mix of poetry, folk, rock and ambient music.

The site lets you post comments on what you've heard and you can share tracks with others too.

My favourites were a well-produced bossa nova track called Jazz Feliz, and what sounded like a gang of disabled people shouting "we want access".

One small criticism is that you can't hear 30-second snippets and have to listen to each track from the start.

The sound quality of the recordings I heard varied

from excellent to average, but I quite liked the inclusive aspect of the site.

Keith says that anyone inspired to try their hand at creating music after listening to what others have done should try it, and then maybe make what they've done available on the site.

"I'd encourage disabled people to learn to play music and to consider that the important thing, if you don't have a teacher, is that it's about playing. It's like being a kid when you play with toys. You've got to mess around and make music fun."

Disabled Musicians Direct is the only online site I know of where you can listen to lots of disabled performers in one place. And you're not excluded from the club if vou're artistically talentless either.

 soundcloud.com/groups/ disabled-musicians

#### → Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- · email us editor@disabilitynow.org.uk
- phone us 020 7619 7323

### worklife



#### Life's no drag for Chris

It's a long way from panel beating to making fetish costumes via drag performance, but that's the journey Chris Davis has been on

've always wanted to be female, so I think the drag queen stuff is in my blood. I came out officially as a drag queen when the fetish scene took off in 1984.

I used to organise fetish parties and drag queen events. I'd perform with my drag partner, Brian. Our performances were more gothic than usual, but they were fun.

I'd make the stage clothes myself - I had no machining skills, my skills were all selftaught. Bizarrely, most of my creations got pinched on a regular basis. I remember thinking: "If people are nicking them, there has got to be a

Despite my lack of sight, I can touch a garment and know almost exactly what it looks like, just by running my hands over it. I get a sense of fabric, texture and the shape quite easily

market for them!"

I used to work in the car industry, but when my eyesight deteriorated I had to give it up, so I decided to train as a fashion designer. It was during the six years training where I met my

current partner, Fiona. She revived my interest in the fetish scene so we put our heads together and we started what is now Wicked Waists

Before we set up in business, we had four years together of playing with each other's designs and sketches so even now I've lost my sight completely. I know that when I describe a design to her, her sketch will be exactly what I had in mind. I make up the patterns, cut steel boning for corsets and Fiona does the machine stitching.

Despite my lack of sight, I can touch a garment and know almost exactly what it looks like, just by running my hands over it. I get a sense of fabric, texture and the shape quite easily.

The hardest thing about starting our business was getting regular customers. We've now got quite a few who have been with us now for four years.

There's a good mix of male and female customers, and people from all over the world. We've taken orders from America, Russia, Sweden and there is a lot of

interest from Germany!

Because we are based in Chatham, near Dickensian Rochester, we do a lot of authentic Victorian and Regency costumes as well as really crazy stuff that you wouldn't get in the high street. We've made satinquilted leather dresses. restrictive "hobble" skirts. PVC fetish garments and Chinese-style dresses.

**Everything at Wicked** Waists is made to order and designed by either the customer or myself.

At the moment, we're working on what I call the "Grim Reaper" outfit made for a 6ft guy who wears 18" platform boots. It's a straight coat with a corset crafted into it and a 6ft zip running all the way down to the floor. Even the hood has chains rather than cords. We had to source the fabric (Supergloss PVC) from Korea and the double-ended chrome plated zip was from Japan! It's a work of art, like all our creations. We're really proud of them all.

· Chris Davis was talking to Annie Makoff

#### CHRIS DAVIS: CAREER PATH

- 1989 Panel beater for R.B Hammonds
- 1992 set up American Auto Repairs as a restoration specialist
- 1996 trained as a
- fashion designer (holds a BA (Hons) Fashion Technology)
- 2005-present set up Wicked Waists with partner Fiona Bucknor.



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2009 RENAULT KANGOO 1.6 petrol, auto, 4000 miles manual, full width ramp £9,200



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2006 FIAT DOBLO 1.3 TDI, 35000 miles. manual, lightweight ramp £6,750



2008 RENAULT KANGOO DRIVE FROM W/CHAIR 1.6 petrol, 3000 miles, auto, remote controlled ramp £14,995 plus VAT



**DRIVE FROM W/CHAIR** SWB, 2.2 Tdi, auto, 5000 miles, elec gear select £22,995

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COMPACT wheelchair accessible, over 4 in stock 2004(53) Vauxhall Agila 1.2 Club Liberty, 5sp, 18,000 mls 2006(55) Suzuki Wagon R Liberty 1.3GL 5sp, A/C, 7,000 mls

**MEDIUM** Renault Kangoo 1.2 Authentique 5sp, 44,000 mls Renault Kangoo 1.2 Authentique 5sp, 30,000 mls 2003(03) 2004(04) Renault Kangoo 1.2 Authentique auto, A/C, 38,000 mls Renault Kangoo 1.2 Authentique 5sp, 29,000 mls 2004(04) 2004(54) 2004(04) 2004(04) 2004(04)

Renault Kangoo 1.2 Authentique 5sp, 25,00 mls Renault Kangoo 1.2 Authentique, 5sp, 11,000 mls Renault Kangoo 1.2 Expression, 5sp, 19,000 mls Fiat Doblo 1.4 Low Floor Active 5sp, 14,000 mls Renault Kangoo 1.2 Expression, 5sp, 23,000 mls
Renault Kangoo 1.6 Authentique, auto, 27,000 mls
Renault Kangoo 1.2 Authentique, 5sp, 14,000 mls
Renault Kangoo 1.2 Authentique 5sp, A/C, 11,000 mls
Renault Kangoo 1.2 Expression, 5sp,14,000 mls
Renault Kangoo 1.2 Expression, 5sp,14,000 mls
Renault Kangoo 1.2 Expression, A/C, 5sp, 8,000 mls
Renault Kangoo 1.2 Expression, A/C, 5sp, 8,000 mls 2004(54) 2004(54) 2006(55) 2005(05) 2006(06) 2006(56) 2005(55) 2007(07) 2005(55) Renault Kangoo 1.2 Authentique, 5sp,23,000 mls Renault Kangoo 1.5 DCi, Elap Seat + L. Floor, 12,000 mls 2007(07)

Renault Kangoo 1.2 Authentique, 5sp, 9,000 mls Fiat Doblo 1.4 Dynamic Hi-roof, A/C, 5sp, 20,000 mls 2008(57) Renault Kangoo, 1.2 Authentique, 5sp, 19,000 mls Renault Kangoo 1.2 Authentique, A/C, 9,000 mls Renault Kangoo 1.2 Authentique 5sp, 5,000 mls 2008(57) 2007(07) 2007(57) Renault Kangoo 1.2 Authentique 5sp, 5,000 mls
Renault Kangoo 1.2 Authentique, A/C, 5sp, 3,000 mls
Renault Kangoo 1.6 Expression Auto, A/C, 27,000 mls
Peugeot Partner 1.4 Totem, A/C, 5 sp, 42,000 mls 2007(57) 2008(57) 2007(07) 2008(08) 2008(08) Renault Kangoo 1.6 Authentique auto, 21,000 mls Renault Kangoo 1.6 Authentique auto, A/C, 14,000 mls Peugeot Partner 1.4 Totem, A/C, 5sp, 3,000 mls Fiat Doblo 1.4 Active Low Floor, A/C, 8,000 mls 2008(58) 2009(09)

2009(59) 2010(60) New Renault Kangoo Liberty Delivery Mileage From

FAMILY MPV wheelchair accessible, over 30 in stock 2002(02) Seat Alhambra Liberty, 2.0, S, 49,000 mls 2005(05) Kia Sedona CRDi LE, A/C, 5sp, 41,000 mls 2004(04) Mercedes Vaneo 1.6 Family auto, A/C, 48,000 mls 2006(06) Kia Sedona 2.5, Low Floor ,44,000 mls
Renault Grand Espace, Expression, DCi ,65,000 mls,
Seat Alhambra 1.9TDi SE , auto, A/C, 29,000 mls
Kia Sedona CRDi GS, 5sp, A/C, Full L. Floor, 14,000 mls
Vauxhall Zafira 1.6 Life, 5sp, A/C, Full L. Floor, 18,000 mls
Volkswagen Caddy Max Life 1.9 Tdi, Auto, 9,000 mls
Via Sedona CRDi GS, 5sp, A/C, Full L. Floor 11,000 mls
Kia Sedona CRDi LS, 5sp, A/C, Full L. Floor, 9,000 mls
Kia Sedona CRDi GS, auto, A/C, Full L. Floor, 10,000 mls
Kia Sedona CRDi LS, auto, A/C, Full L. Floor, 11,000 mls
Kia Sedona CRDi GS, 5sp, A/C, Full L. Floor, 11,000 mls
Kia Sedona CRDi TS, auto, A/C, Full Low Floor,
Kia Sedona CRDi TS, A/C, Full Low Floor,
Kia Sedona CRDi TS, A/C, Full L, Floor, Kia Sedona 2.5, Low Floor, 44,000 mls 2005(54) 2005(55) 2007(07) 2008(58) 2009(58) 2008(08) 2008(08) 2008(58) 2008(58) 2009(59) 2010(59) 2010(60)

LARGE wheelchair accessible, over 25 in stock

2004(04) Citroen Dispatch 5sp, 5 seats, 46,000 mls Citroen Disparch 5sp, 5 seats, 46,000 mls
Renault Master 5sp, 5 seats, Chairlift, 36,000 mls
Renault Master 5sp, A/C, 5 seats, Ramp, 27,000 mls
Volkswagen T5, 5sp, A/C, 5 seats, Chairlift, 14,000 mls
Renault Master 5sp, A/C, 5 seats, Chairlift, 15,000 mls
Fiat New Scudo 5sp, A/C, 5 seats, Low Floor, 28,000 mls
Renault Master auto, A/C, 5 seats, Chairlift, 5,000 mls 2004(04) 2007(07) 2007(07) 2008(08) 2008(58) 2009(58)

WHEELCHAIR DRIVER

25 in stock including 2002(02) Mercede Vito, Auto, Drive from Wheelchair, choice 2005(05) Suzuki Life Drive from Wheelchair, choice of 4 from 2005(05) Mercedes Sprinter, Powered Transfer Seat, 25,000 mls 2008(08) Sirus Kango, Drive from Wheelchair, Choice of 5 from Kia Sedona Pilots, Drive from/Front Passenger, Choice 2008(58) Renault Solus, Drive from Wheelchair, 1,000 miles only
Volkswagen Sirus Caddy, Drive from Wheelchair, choice frm
£24,995 2009(09) 2008(57) Chrysler Grand Voyager, XS, Drive from Wheelchair / S x S £29,995

£6.595 £4,995 £5,995

£6,195 £6,395 £6,495 £6.495 £6,595 £6,695 £7,195 £7,295 £7,395

£7,995 £8.195 £8.295 £8,295 £8,395 £8,495 £8,495 £8,495

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£10,195 £10,295 £13,995

£9,295 £8,995 £9,995 £10.395 £11,595 £12,995 £17,995 £18,995 £19,395 £19,695 £20,295

£20,995 £21,695 £22,995 £23,995 £26,995

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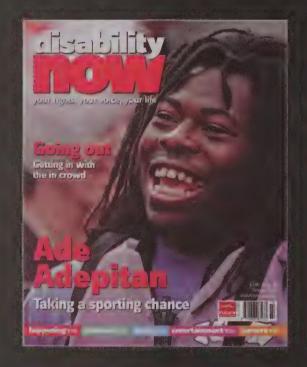
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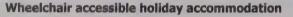
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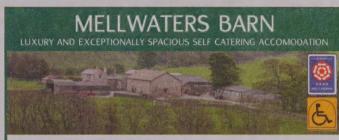
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### backlash



### Citizen Carter's good cause

Though cowards flinch and traitors sneer, **Paul Carter** is calling us to the barricades, and this time he's serious

ou can't possibly have failed to notice that protest and social unrest has been the order of the day recently. Certainly, for the last couple of months, it's felt like barely a week has gone by without some ragtag group or other kicking off over something or other.

That's not a bad thing – I think protests are brilliant. Not least for the fact that you get to stand around all day looking like you're really menacing and threatening when in actual fact your main hobby is floristry, you live with your mum and you have a cat called Petal. (FYI I'm not referring to me).

Such silliness is actually a preamble to a serious point I'd like to make. For once. On 11 May, a protest is being organised in London in which disabled people will march against the swingeing cuts to disability benefits and services being carried out by the coalition Government.

Now, I'm going to stick my head above the parapet somewhat here and say that, when it comes to mass



protest and organisation, disabled people have always been a bit, well, crap. Sorry, but it's true.

Us disableds do like a moan. And, quite often it has to be said, as a movement we tend to misdirect our anger and our passion in the wrong places. Usually at each other, and it all too often descends into infighting and complaining to the point that the whole thing becomes a waste of time before it's even got started.

This time has to be different. And it will be different. For the first time in as long as I can

remember, people are actually working together. Charities and DPOs are coming together to get people mobilised and to get their voices heard. To get OUR voices heard.

Yes it will be difficult for some of you to get out because of social care problems, because of inaccessible transport, because of lack of benefit. But if we do nothing, and we don't speak our minds, those problems will get worse. If you cannot make it, then the internet and social media has opened huge numbers of doors to make it easier to protest

Us disableds do like a moan. And, quite often it has to be said, as a movement we tend to misdirect our anger and passion in the wrong places. Usually at each other

and have a voice.

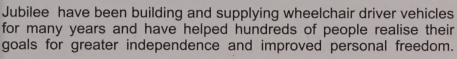
Whatever your politics, the fact that disabled people are a group being hit hardest by the Government's cuts programme is inescapable.

Men, women, children, assistance dogs. Whatever. Every single one of us needs to stand up – or sit down – and be counted. It needs all of us together. Every single one of us.

I'll be there. Come and say hello. I'll even let you buy me a beer if you're really nice. However if it kicks off and a rumble starts I'll be out of there quicker than you can say "anarchist." I'm dedicated to the cause, but I'm more dedicated to my face.

### Wheelchair Drivers

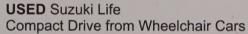
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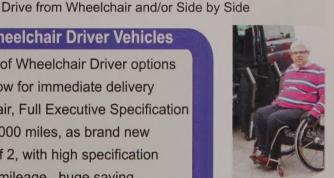


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	2009	Renault Solus, Drive from wheelchair, less than 1,000 miles, as brand new
	2008/9	VW Sirus Caddy, Drive from Wheelchair, choice of 2, with high specification
•	2009	Mercedes Sprinter, Drive From or Transfer : Low mileage , huge saving
•	2006	Volkswagen Transporter T5 High Roof. Powered doors and transfer seat.
•	2007/8/9	Sirus Renault Kan-gos. Choice of 5 from just 1,000 miles. High specifications

2007/8/9 Kia Sedona Pilots Choice of 3. Drive from wheelchair and/or side by side. 2005/6/7 Suzuki Life's, Drive from wheelchair compact cars, Choice of low mileage models

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